



NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

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Scott Allen

Dear Scott:

The ol' flu bug got me down and I had a hard time getting up. Hence, my canceling out of the Chicago meeting. I am really sorry about that for a number of reasons and one of them prompts me to write this letter. Since there was no advance agenda of the business meeting, I don't know whether your working group report on social/human issues was discussed, but had it been, I would have shared the comments that I will make in this letter.

The report is comprehensive and reflects a great deal of work on the part of you and the other working group members for which I am personally very grateful. It also reflects the concern of caring for people with HIV that represents the perspective of our entire commission. It is well crafted, and clearly organized and reflects a depth of the human dimension of this disease.

I want to voice some concerns of emphasis in several areas of the report. On page 3 of the draft under Delivering, Coordinating and Paying for Services, the report says the planning process ought be supported by responsible government. I would suggest that planning ought to be initiated by the entity of government responsible for public health in a community. That is clearly the position and recommendation of the National Association of Counties with respect to its own county constituencies where counties are charged with the responsibility of protecting the public health of the community. (See attachments)

On the bottom of page 3 the report states that "voluntary organizations should coordinate local efforts," etc. In my experience that would often be inappropriate and non productive particularly when it is most often governmental entity at the local level, which by law has the responsibility for public health.

This section relating to Delivering, Coordinating and Paying for Services, seems to put the emphasis on the voluntary, private sector that tends to allow the government a "supporting role." In most areas this does not meet reality. I suggest it is the government that ought coordinate and initiate and take the lead in the planning effort which involves the private/volunteer sector in that process.

I am convinced in my own state that the reason Minnesota's projections for HIV infection have dropped so dramatically is, at least in part, due to the leadership of our state, county, and (two cities) public health departments who worked closely with the volunteer sectors to develop plans to address this epidemic at every local level. This "public perspective" is very important to incorporate into the recommendations because without it I believe most of the country would not be able to address meaningfully a coordinated local effort. Where that public sector is weak it needs to be "shorn up" and not dismissed or bypassed. It may be that voluntary organizations have the responsibility, the power, and skill to coordinate local efforts in some large coastal communities. I do know that this is not the case across this country.

Also on page 3, "government support" (meaning funding) is stated as critical for voluntary agencies. It is also critical for governmental agencies that are providing a large share of the service and educational needs to address HIV. In my own community, it is the public health department that provides the case management medical care and provides or funds many of the educational programs available in the community. My own county has funded for 3 years an AIDS coordinator in our public health department, whose function is both education and coordination and that funding comes from our local property tax. We must be as supportive of the public efforts to address community and individual needs as we are of the private effort. Particularly so as the report points out on page 44 that it will be that public effort that will provide the major service source to poor people increasingly infected.

In reading pages 9 and 10, I would suggest there is another troubling aspect of early intervention (i.e. testing), another ethical issue, that ought somehow to be a part of this discussion. That has to do with the need for testing to prevent, or at least try to prevent, further infection. Recently, I heard testimony in the twin cities from a young couple, both of whom were infected.

The man said he postponed being tested because he was afraid of what he would find out. His partner's testimony was rather different. She asked, "Why did he do this to me--why didn't he get tested? He might have prevented my infection." This is another side of early intervention, with ethical implications, which I think ought to be incorporated in the ethical dilemma.

I would also like to suggest that the last 15 or so pages of the report be carefully read in terms of the need for some further inclusion and shoring up of the public health system. My reading of it reflects a constant concern for funding the voluntary sector, but what about funding the public health sector as well?

Again, on page 44 the report states that the public health system is becoming a provider of direct health care services or provider of last resort. (In areas I am familiar with, we have been this for some time.) It seems to me it is important in our report that we show equal concern for both public and private systems, otherwise we may be left with a thousand points of light and an eroding public base.

Once again, I am really sorry I missed you in Chicago and look forward to our April meeting.

With warmest regards,

Diane Ahrens

DA/gb
Attachment

P.S. I am attaching the recommendations made by the National Association of Counties to the counties across this country with respect to the public counties role in addressing this infection.

cc: National Commission on AIDS Members
Maureen Byrnes